

Submission: Patricia Stillman (*individual*)

I was diagnosed with RP (Retinitis Pigmentosa) a degenerative eye disease at age 31. At the time I was Night Supervisor of an 80 bed surgical & medical private hospital in a regional city.

Clearly understanding that a future as a registered nurse was not feasible I approached a number of services seeking information about re-training but was only advised to keep working as long as possible.

Age 33 (1978) I was declared legally blind and immediately advised to stop working due to legal ramifications for the hospital should any adverse incidents occur when I was on duty.

Again I approached services such as CES (now Centreink), Commonwealth Rehabilitation (now CRS) and Royal Blind Society (now Vision Australia). Apart from RBS suggesting I move to Brisbane or Melbourne the only support I was offered was DSP (Blind).

Since 1979 I have not worked in paid employment although I continue to be involved in a number of organisations on a volunteer basis. After retiring from nursing I worked as a Granny Sitter, sold Lucky Number tickets and motel cleaner. I continued to work at this type of job until an MVA resulted in me spending almost two years recovering from my injuries. Rest assured I was not the driver – I relinquished my driver's license in 1979.

Recently I made email contact with a woman in the UK who is my age, a registered nurse and was whom was diagnosed with RP at age 31.

Unlike me, my UK counterpart was offered a lot of support to keep her fully employed in the health system where she continued to work until retired in 2009 aged 63. Low vision equipment provided during her working life is now her personal property.

Under UK system she was provided with equipment and retraining at all stages of her vision loss enabling her to continue working competently without danger to herself, patients or other staff. As well as providing financial security it also helped her retain self confidence and the feeling of being valued as contributing to her community and the well being of her family.

Now aged 64 this woman has superannuation to enable her to live comfortably into her later years plus be able to afford to replace her expensive low vision equipment or buy new equipment.

On the other hand I do not have superannuation – this was not available to nurses in 1978 which means apart from DSP (blind) I have no real financial security. I have been dependant on government benefits for over 30 years when I could have been productive had I been offered the support I think a National Disability Insurance Scheme should offer.

I was provided with a CCTV (electronic magnification unit = \$5,000) and a laptop with screen magnification software (\$3,000) by CRS in 1990 when I was doing a degree. Since then I have replaced the CCTV (with a 2nd hand unit from a deceased estate) and the laptop with at least two computers – at this time both my CCTV and computer are out of action and I am saving to purchase a new computer.

Each time Microsoft release a new version of Windows I have the expense of updating my screen magnification software (Zoom Text) – this usually costs around \$250. I am still using Windows XP and had hoped to continue to do so for at least another 12 months but today my IT guy informed me my 10 year old system is declining rapidly and he considers it is on its final repair.

A little about my life story: I grew up in a small country town, one of ten children born the year after my father was demobbed having served in the AIF for 5 years. I was raised knowing it was important to get an education, contribute to your community and work for your daily bread.

My first paid position was at age 10 capping milk bottles using a foot pedal at the local dairy. Over the next four years I did a number of after school & holiday jobs including baby-sitting, fruit picking, washing bottles at the soft drink factory, packing stationary at the local news paper and shop assistant in a café. As well as this paid work I did volunteer hospital and aged unit visits where I read to older people, wrote letters, shopped and cleaned cupboards. I was also involved in sport, church & youth groups.

After completing my secondary education I worked as a receptionist prior to commencing nurse training at 17. I married soon after graduating but continued to work until retiring due to vision loss, apart from a few months off to have each of my 2 children.

I undertook courses in the hope of finding employment but with strong competition from “normal” candidates I was not successful. I may have been more successful if I had moved to a capital city but

I was raising two children on my own by the time I was declared legally blind and consider I had more control over them living in the area we knew and were known. This proved to be the right choice as both my children have always been in employment and are leading happy and successful lives.

So you can see I was willing to work and thought I would work until retirement age. Now aged 64 I still dislike being dependant on government benefits and regret the wasted years.

A few thousand dollars spent on special equipment and a system of re-training before a disability becomes a handicap would keep more people with degenerative conditions in the work force thus keeping skilled workers.

Patricia Stillman BA; DIPLOMA COMMUNITY SERVICES; DIPLOMA HUMAN SERVICES: WORKPLACE TRAINER.

Volunteer Positions

Blind Citizens Australia Women's Branch committee member

Vision Australia I-Access Advisory Committee Queensland representative

Guide Dogs Queensland Peer Support team member

GDQ Client Liaison Committee member

DSQ Wide Bay Burnett Regional Disability Council Vice Chair

Retina Australia (Qld) Peer Supporter

Bundaberg Regional Council Access Reference Group member

Bundaberg District Blind & Vision Impaired Peoples Friendship Club resource & information officer

Coral Coast Community Radio (94.7 FM) Community Access RPH committee member.